

PDBP DMR Global Unique Identifier Tool (GUID) For ProFoRMS

How to use the PDBP DMR GUID Tool for ProFoRMS

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1. PDBP DMR GUID Tool for ProFoRMS

The PDBP DMR is a restricted access portal designed as a tool to support Parkinson's Disease Biomarkers research projects. A PDBP DMR account is required to submit or access Parkinson's Disease Biomarkers-related data. Investigators and data managers at research sites are invited to request an account. To provide maximum protection for the confidentiality of research participants whose data is stored in the PDBP DMR, professional credentials are verified by the PDBP DMR staff during the account request process.

In the PDBP DMR, research data associated with an individual subject are linked by means of a Global Unique Identifier, GUID. The GUID is a subject ID that allows researchers to share data specific to a study participant without exposing personally identifiable information (PII). GUIDs allow investigators to track participants longitudinally, across multiple research sites and across multiple studies. It is important to remember PII is never sent to the PDBP DMR system and that the GUID is a random number not generated from PII.

There are (2) functions of the GUID Tool:

1. Create GUID
2. Search if GUID exists in PDBP DMR

2. Using the GUID tool in ProFoRMS

Researchers collect PII from their participants and store that data in a local database that is not made available outside the research institution and is governed by the institution's local rules and regulations. The GUID tool is an application that is downloaded and launched from the PDBP DMR website and run locally on a user's computer. This software performs a one-way encryption, often called a one-way hash, which determines if the research subject hash codes have been seen previously by the PDBP DMR. A one-way hash is a reproducible method of turning some kind of data into a (relatively) small number that may serve as a digital "fingerprint" of the data. The algorithm "chops and mixes" (i.e., substitutes or transposes) the data to create such fingerprints. The hash represents the "fingerprint". However, it cannot be used to recreate the original. In other words, the encrypted hash codes do not have information to recreate the PII, however, the GUID does provide enough information to determine if a research participant already exists in PDBP DMR.

2.1. Prerequisites for running the GUID tool in ProFoRMS:

- Valid PDBP DMR account with GUID privilege (PDBP DMR Request Additional Account Privileges if needed)
- PDBP DMR opened in Firefox
- Java Runtime Environment (JRE) installed on your computer (Version 6 or higher)
<http://docs.oracle.com/javase/7/docs/webnotes/install/index.html#windows>

2.2. Create GUID

After you have ensured that you have met all the prerequisites, you are ready to generate GUIDs in ProFoRMS. If a GUID has already been created for a subject, see the section titled “Validate if GUID exists in PDBP DMR” below. However, given identical PII inputs, the system will regenerate the identical GUID for the subject and this will not result in two subjects.

This procedure provides the steps necessary for using the GUID Tool. The entire procedure time varies depending on the number of GUIDs being generated.

1. In Firefox, open the PDBP DMR website at <http://pdbp.ninds.nih.gov>
2. Log in to PDBP DMR
3. Click on ProFoRMS
4. Click on Manage Subjects
5. Click on Add Subject
6. Answer “no” to the question: “Does this subject have a GUID?”
7. Enter in all required fields in both columns. Double-entry format is designed to reduce errors.

Note:

- a) Do not use abbreviations for city of birth. For example, do not use NYC for New York City or LA for Los Angeles.
 - b) The last two fields (Government Issue ID (GIID) and Country of GIID) are optional. However, if you enter in information for #11, you must also fill out #12.
8. When all fields are complete, click the Generate GUID button
 9. If all fields are successfully entered, the window will display a textbox with the new GUID and a “Valid GUID” icon. If you wish to enter your site’s subject ID and/or the Biorepository Subject ID so that you can search for this subject by those ID’s, enter that information into the displayed text boxes. Alternatively, you can add this information later with the Edit Subject feature.
 10. Click Save
 11. Copy and paste GUID directly from GUID box into your local repository associating GUID with your subject.

PII Field Name	Required for valid GUID?
Complete legal given name of subject at birth	Yes
Complete legal family name/surname of subject at birth	Yes
Complete additional legal name or names at birth	Yes
Day of month of birth	Yes
Month of birth	Yes
Year of birth	Yes
City or municipality of birth	Yes
Physical sex of subject at birth (M/F)	Yes
Country of birth	Yes
Indicator if subject has NO middle name at birth	Yes
Government Issued / National ID (for the United States, this is the Social Security Number)	Optional
ISO 3166 STANDARD letter abbreviation of the country of origin of the GIID.	Optional

Table 1: GUID PII information

2.3. Validate if GUID exists in PDBP DMR

If a GUID has already been created for a subject (for example, in the GUID BRICS tool), please use the instructions in this section to validate the GUID and add it to the My Subjects section of ProFoRMS so that visits can be scheduled and form data collected. Keep in mind, however, that given identical PII inputs, the system will regenerate the identical GUID for the subject and this will not result in two subjects.

1. In Firefox, open the PDBP DMR website at <http://pdbp.ninds.nih.gov>
2. Log in to PDBP DMR
3. Click on ProFoRMS

4. Click on Manage Subjects
5. Click on Add Subject
6. Answer “yes” to the question: “Does this subject have a GUID?”
7. Enter the GUID into the GUID or pseudo-GUID textbox
8. Click Validate GUID
9. If the GUID is valid, a “Valid GUID” icon will be displayed and the subject will be added to My Subjects.